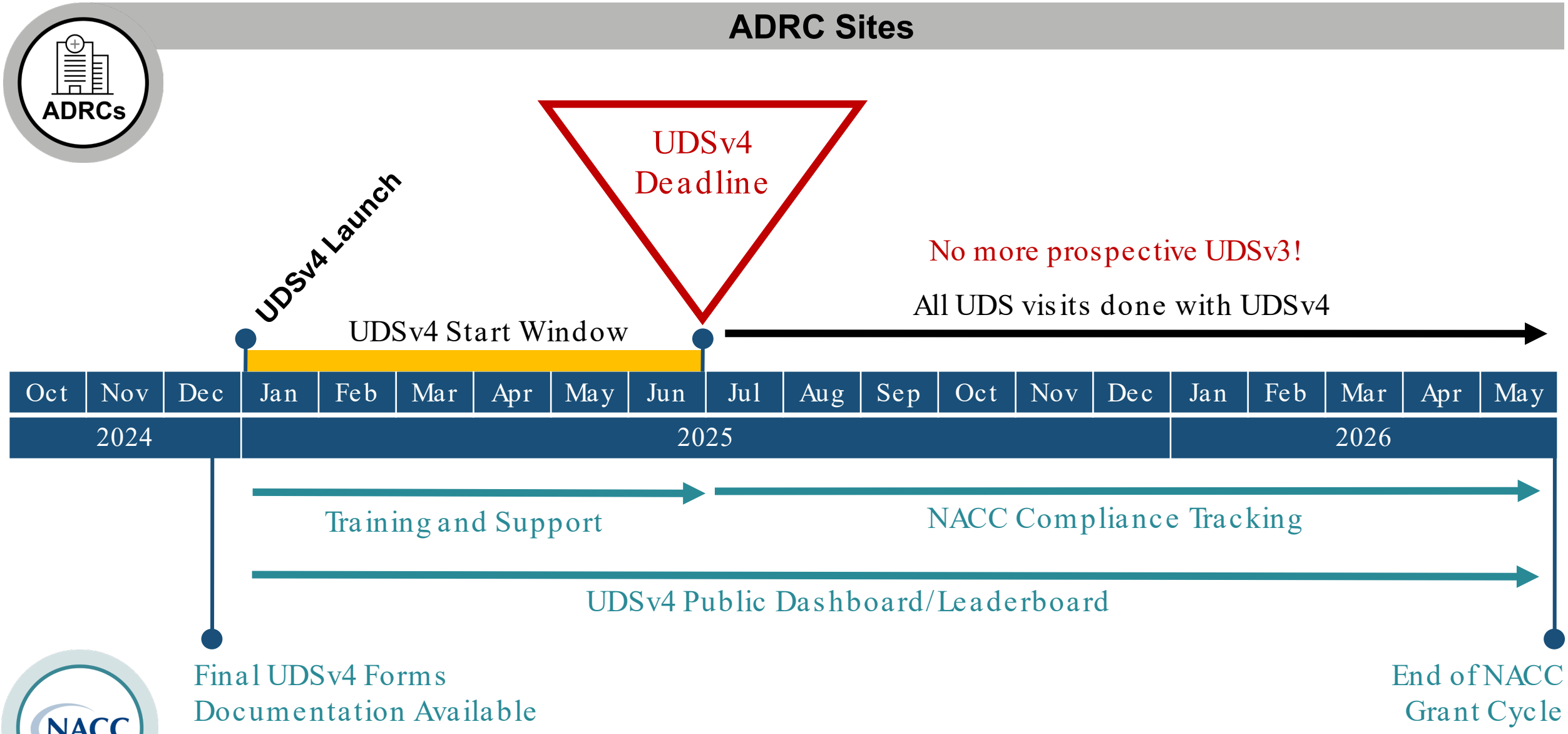
ADRC Pilot: Qualitative Results

Moderated by: Suzanne E. Schindler, MD, PhD; Washington University

ADRC Fall Meeting, October 17

UDSv4 ADRC Launch

ADRC Sites



NACC

General comments on UDSv4 were mostly positive

- “Most of the forms were relatively unchanged, and considering our experience with UDS 3.0, we had an understanding of how to fill them out.”
- “Our research assistant felt that the new forms had better branching logic”
- “While completing these forms takes a noticeably longer amount of time due to the additional questions and forms, the additions are incredibly relevant to the current state of ADRD research and will allow for greater breadth and robustness of significant research (especially regarding SDOH).”
- “…jokes aside, all of the existing materials and documentation have been really helpful throughout the past 18 months or so.”

Do not under estimate the IRB process!

- “IRB approval took forever…”
- “The best help we could receive at this time is patience as we work on IRB approval for udsv4. This will take many months at a minimum, in particular for one of our clinical sites (a VA hospital, their IRB takes a very long time to review submissions).”
- “Our experiences working with the IRB for the pilot, prompted us to think different about our IRB application for UDS4 rollout. We are going to be planning on a much more complicated and time-consuming IRB experience during implementation.”

More site-specific training is necessary

- “We learned that we need to develop more internal trainings and guidelines that are more detailed (and site-specific) than the NACC provided training content…”
- “We are planning more specific staff training to ensure the team is ready as many stated aspects of the virtual workshop was helpful but didn't deal with ‘how to actually administer UDSv4 and how to handle potential patient questions’.”
- “We plan to have extensive training regarding the new forms and protocols, particularly related to the new A1a SDOH, the D1a Clinical Syndrome, and D1b Biomarkers Used To Support Etiological Diagnosis forms.”
- “We will have to go deeper into understanding the SCI and MBI criteria and making sure all of our clinicians and coordinators are understanding.”
- “Preparation for coordinators to handle possible stress reaction from the participants in relation to new questions.”

Consider logistics including scheduling

- "…we realized that UDS4 implementation will need to be a very carefully organized series of events."
- "We plan to take the next few months to integrate the UDSv4 into our current processes and site-specific data collection/processes as well to look for efficiencies and reduce redundancy."
- "We will coordinate all visits as though they are initial visits."
- "We will also have to add more time to our visits (especially for clinicians), and consensus meetings."
- "We will heavily emphasize for participants to complete the A1 and A1a, as well as our revised A4 and A5/D2 intake form, beforehand."

REDCap forms and data upload worked very well!

- “We will be switching our UDS data collection system to redcap! Very impressed with redcap interface.”
- “All worked relatively well. The forms were more or less formatted identically to the UDS 3.0 forms. Any new types of data entry came with accessible directions.”
- “Forms were well designed and easily imported.”
- “Direct entry intro RedCAP made it easy to figure out what needs to be asked and what doesn't need to be asked based on the participant's answers.”
- “The upload of csv file was easy. Will be interested to know how the error-checking will work with that option, as well as the API option”

Requests for additional guidance/resources

- “…detailed summary of changes for implementation of UDS4 and a crosswalk between USD3 and UDS4 that can be submitted to IRBs.”
- “…checklist of items that each site needs to complete in their prep work for UDS4 implementation”
- “Running through sample scenarios on how to best fill out the forms.”
- “I think it's important that there ALWAYS be an organized place where questions can be asked and answered in a timely manner and available for everyone to reference.”
- “Further training or support regarding the A4a ADRD Specific Treatments form would be great.”
- “We are looking into educational materials that provide lay friendly background on SDOHs.”

Responding to your Pilot Feedback

A collaboration between NACC, CTF, and the EDC Workgroup

- **General**
  - Website with centralized resources
  - Additional implementation time

- **Clinical**
  - Updating some forms and clinical guidance documentation
  - Additional clinical trainings and webinars
  - Boiler plate language for IRBs
  - Clinical support via the ADRC Community Forum
  - Recommend forms that can be sent to participants in advance

- **Technical**
  - Changes to REDCap form logic and rules
  - More accessible API documentation
  - Hosting a sandbox environment where ADRC can practice data submission

UDSv4 Support and Resources

General

- Onboarding Checklist
- Community Forums
- Office Hours
- FAQs
- UDSv4 Website

Clinical

- Forms & Coding Guidebooks
- Training Webinars and Videos

Technical

- REDCap Forms and Resources
- dVoice Forms and Guidelines
- UDSv4 GitHub Library
- Data Collection Options
- UDSv3 to UDSv4 Crosswalk
- Data Submission Options
- NACC Data Platform Sandbox
- Training Webinars and Videos

Acknowledgements

- Clinical Task Force: Cindy Carlsson and Greg Jicha
- NACC: Sarah Biber, Jessica Culhane, Kathryn Gauthreaux, Elise Gruber, and Hannah Rosentreter

Thank you to the sites that participated in the pilot!

Panel on UDSv4 Pilot

Justin Barber, MS	University of Kentucky ADRC
Anna Campbell Sullivan, PsyD	South Texas ADRC
Nicole Oliviera, BS	Penn ADRC
Eric Steinberg, NP	Boston University ADRC